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**“I have learnt to love the child and give opportunities to play with peers’.”  
A feasibility study of the training programme to support parents of young  
children with visual impairment in Malawi**

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## **Abstract**

This is a first mixed-methods study, which created, adapted and tested the feasibility of a training programme targeted at parents, community professionals, specialist teachers and volunteers to provide advice on developmental stimulation for children with visual impairment (VI) in their homes in rural and urban settings of Malawi. The study followed guidance from the MRC Framework for Developing and Evaluating Complex Interventions and drew on a bioecological model to help understand the feasibility of a new intervention in Malawi for 30 children with VI and their carers in three districts of Southern Malawi. We trained 14 community workers and specialist teachers, then piloted the programme, which we linked to WHO UNICEF Care for Child Development, over six months. A total of 10 observations were carried out to measure fidelity of the intervention at the child's home. Acceptability was accessed through 20 post intervention interviews and a focus group discussion with carers. Findings show that the new programme enabled workers and parents to be more positive towards their children with disabilities, improving relationships and responsiveness in their interactions. Drawing on the findings of the feasibility study, outcomes identified for a trial include measures of communication, child development, family care environment, participation and inclusion. This study has significance in providing a methodology that can be drawn upon to develop similar training programmes for use with children with a wider range of disabilities. The paper has particular relevance to institutions and organisations working in early childhood development in that it provides a model to aid the development of tailored training programmes for children with VI. It puts forward a table of ten key messages on how best to prepare young children with VI for life at school and for life after school.

## Introduction

Early childhood development (ECD) is considered to be a significant phase of growth and development that influences outcomes across an individual's entire life and provides an important window of opportunity to prepare the foundation for life-long learning and participation (WHO, 2012). An estimated 150 million persons have a disability globally with up to 17% of them being children (WHO, 2011). Visual impairment (VI) is one of the most common causes of disability in children with up to 19 million below the age of 15 affected. In Malawi, the prevalence of childhood blindness is estimated to be as high as 0.7 per 1,000 (ICED, 2014). The Ministry of Gender, Children, Disability and Social Welfare (MGCDSW) promotes equal access to over 100 different service providers (including eye care health services) which are mainly located in large towns and cities across the 28 administrative districts (Malawi Govt., 2013). The cost of education, (re)habilitation and lost productivity due to blindness is a significant economic burden particularly in economically deprived areas of the world (WHO, 2006, Rahi and Cable, 2003).

Although there is little detailed information on childhood disability in low income settings such as Malawi, the 2008 Malawian national census estimated disability (as reported by the household respondent) among children to be 2.4% with hearing loss the most common cause (23%), followed by visual impairments (17%). More recently, a 2013 study in two districts in Malawi (Ntcheu and Thyolo) estimated the prevalence of disability among children to be 1.7%. Among the children surveyed, clinical assessment revealed physical impairments were most common (39%) followed by hearing impairments (27%), intellectual impairments (26%), epilepsy (22%) and bilateral visual impairment (4%). Despite the population of Malawi being relatively small at approximately 16 million, according to the 2008 census nearly half are under 15 years (ICED, 2014). This meaning there are potentially between 136,000 and 192,000 children living with disabilities of whom over 32,000 may have a visual impairment.

Evidence suggests that if young children with VI do not receive appropriate stimulation, they do not acquire the skills to develop well (Dale et al., 2015; Dale and Sonksen, 2002; Sonksen and Dale, 2002). Research has shown that programmes, which promote early development and maximise the use of functional vision for children with visual loss can make a difference in the longer term (Dale et al., 2014). Examples of such programmes include the 'Developmental Journal' (DfES, 2006) and the Oregon Project (Anderson, et al., 2007). These programmes empower parents to provide timely support for their children along a developmental trajectory and enable better co-working with professionals (Dale and Salt, 2007).

Over the past 15 years, global interest in promoting ECD has increased exponentially with emerging evidence for the effectiveness of combined basic sectoral health, stimulation, protection and nutrition programmes particularly if provided in the first 1000 days of life (Black, et al., 2016). The recent UN Sustainable Development Goals (SDGs) prioritises early child development (target 4.2) thus promoting 'access to quality early childhood development, care and pre-primary education'. Prior to this, the World Health Organisation (WHO) and UNICEF had already created a shared programme for encouraging improved maternal child interaction, responsiveness, play and early communication in the first few years of life through 'Care for Child Development' training (WHO, 2012). Although this provides minimal guidelines on how to check for sensory impairment, it makes no provision for children with disabilities. There are notional references to childhood disability but nothing within the training provides parents with practical information to guide them when raising a child with a disability. Separate initiatives have been undertaken by the WHO, through the Community Based Rehabilitation Guidelines (WHO, 2010a) and the mhGAP interventions for mental health and

neurological conditions in non-specialized settings (WHO, 2010b); however, these do not link specifically to early years programmes and are very non-specific. Despite this burgeoning of programmes for improving early child development, evidence on how best to develop, implement and evaluate these programmes remains sparse (Yousafzai and Aboud, 2014; Yousafzai et al., 2014). The only programmes available at present for children with VI are based on more intensive input from specialist teachers of the visually impaired in high income countries (Dale and Salt, 2010).

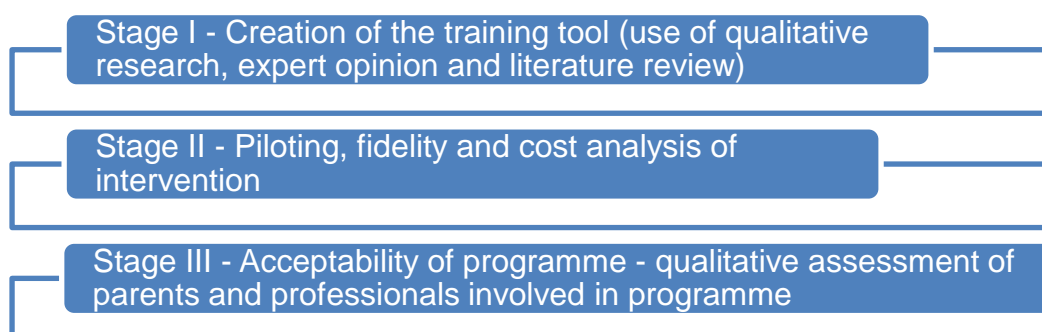
## Overview of this study

The aim of this study was to create, adapt and test the feasibility of a training package on ways to support the developmental stimulation of children with VI in their homes in Malawi. The package was aligned with the Care for Child Development (CCD) and incorporated newly created materials to ensure cultural relevance to young children with VI in Malawi. The multi-disciplinary research team included academics from the Visual Impairment Centre for Teaching and Research, University of Birmingham, the Department of Women and Children's Health, Institute of Translational Medicine, University of Liverpool, Sightsavers and Montfort Special Needs College, Malawi. A full-time Malawian research assistant was recruited to carry out the fieldwork in the three districts as well as a small team of translators.

## Methods

We used a mixed methods approach following guidance from the MRC Framework for Developing and Evaluating Complex Interventions (Craig et al., 2008).

The first objective (Stage I) was to draw on our prior qualitative work which identified the barriers to the provision of a developmental stimulation programme for children with visual impairment in Malawi (Gladstone et al, 2017), and then to review the literature on existing parent-carer training programmes for children with VI before consulting with specialists who work in the field of early childhood development and VI in the UK (e.g. RNIB). Our second objective (Stage II) was to run a feasibility pilot study of a parent –carer training programme over six months with a cohort of families and their children with VI aged 0-6 years in Southern Malawi and to measure fidelity of the programme by collecting information on the number of visits. Our third objective (Stage III) was to gain an understanding of the perceptions of families and professionals relating to the main facilitators, barriers and acceptability of providing this programme.



### **Figure 1: An outline of the three stages of the 18 month study**

#### **Study setting**

We conducted this study in the Southern region of Malawi in two rural (Chikwawa and Blantyre Rural) and one urban (Blantyre Urban) districts from March 2013 to March 2014. We targeted one of the most disadvantaged regions of Malawi with high levels of poverty, malnutrition, vitamin A deficiency and active trachoma (Kalua, 2009). We also set up an advisory group comprising carers who have children with VI and professionals involved in providing ECD services to children with disabilities in Malawi (e.g. District Education Office). The group met three times to provide information and advice on where to advertise for children and families for the feasibility study and to provide feedback on the training materials and programme for children with VI in home-based settings.

#### **Ethics**

All selected families received structured written and verbal information about the purpose and procedures of the study. We obtained written informed consent from each participant. Ethical approval was granted by the College of Medicine Research Ethics Committee, Malawi (P.11/12/1307) as well as *institution withheld*. (ERN\_12-091).

#### **Sampling and recruitment**

We sampled a range of carers and community workers (child protection officers, specialist teachers and CBR workers) in each of the three districts and used key informant methods (Gona et al., 2010; Mackey et al., 2012) to identify children with VI from three selected districts. All children who met the inclusion criteria (aged 0-6, not attending primary school, registered blind /severe visual impairment) were followed up for verification either through visits to homes or phone calls. A final stratified sampling matrix (see table 1) was developed based on the data from the questionnaire and clinical records to ensure there was an even representation of children with different levels of visual acuity, a range of ages (between 0 and 6 years) and sex.

We selected 30 out of 70 identified children - 24 children had low vision and six were blind, aged between eight months and six years (see table 1). Forty of the 70 children not recruited for the study either were of school age or did not have a clinically diagnosed visual impairment when the RA had visited the family. Fourteen community workers who were normally stationed in the three districts for their work also agreed to participate in the study.

**Table 1: Final recruitment matrix for children with visual impairment and paired community workers in Chikwawa, Blantyre Urban and Rural Districts and 20 semi-structured interviews post-pilot.**

Setting	30 Children with visual impairment < 6 yrs.		Community workers supporting families of children with visual impairment <6 yrs.	
	Female	Male	Female	Male
Rural Chikwawa	6 (4)	2(2)	3	1
Urban Blantyre (BT)	3(2)	4(4)	4	4
Rural Blantyre (BT)	6(2)	9(6)	1	1
<b>Totals for each group</b>	<b>15(8)</b>	<b>15(12)</b>	<b>8</b>	<b>6</b>

<b>Totals:</b>	<b>30 (20)</b>	<b>14</b>
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### ***Data collection and fidelity of intervention***

Each community worker was issued with a logbook, which was used for planning, and implementing all visits to a child (planned once every two weeks over 6 months). They were required to enter logistical data (the date and time of visit, distance to the child's home, form of transport used and length of visit) as well a description for not being able to carry out the visit e.g. carer not there, refused to see community worker, bad weather conditions, etc. All entries were checked and verified by the RA during visits to the families and clarification was sought for any queries or missing information.

As part of the fidelity of the intervention, the RA carried out 10 visits on eight female and six male children 6 weeks before the end of the pilot. Using an observation tool, data was collected on demographics of the child, time taken to travel to the child's home, mode of transport used to visit the home, length of session observed, cost of travel, modules and materials used during training as well as quality of information shared during the visit (partly through inspection of log-books). Post-intervention IDIs were carried out to 20 of the 30 carers of children as well as a focus group with six carers to support triangulation of the data from the interviews which were all transcribed and translated.

### ***Framework for analysis***

We imported the quantitative data into spreadsheets to carry out calculations of time and costs and overall research costs over the 6 months. Transcripts were checked for quality and analysed using QSR NVIVO 10. We utilised a framework approach based on Bronfenbrenner's bioecological systems theory which enabled us to understand how our intervention affected not only the child, but the family and the wider environment (Bronfenbrenner, 2005; Niemann and Jacob, 2000). We considered 'enabling environments' at different levels: principally through the individual (the child) in terms of individual engagement or participation; the microsystem level, through the support of family, peers, the church and school; the mesosystem and exosystem levels, through appropriate services and local policies which support the child and family. We made some considerations of the macrosystem level through a greater understanding of changing local and national policies (e.g. Malawi ECD Policy), attitudes and cultural understandings.

### ***The research team and reflexivity***

We drew upon the COREQ reporting checklist (Tong et al., 2007) to help us to decide on how to introduce the study to our participants and how best to deal with questions about the logistical arrangements of the study. Both the coordinator and the RA were both from Southern Malawi and spoke Chichewa fluently. The RA had been receiving training in ECD and special needs education to degree level when recruited and the coordinator had already received a Masters in Special Needs Education. The RA carried out all the observations and IDIs during the study and received training from the UK principal investigator (PI) and co-investigators (Co-I) (both white males who specialise in education and visual impairment) on how to use the data collection tools. The Co-I, a white female doctor from the UK, provided external advice and support to the project.

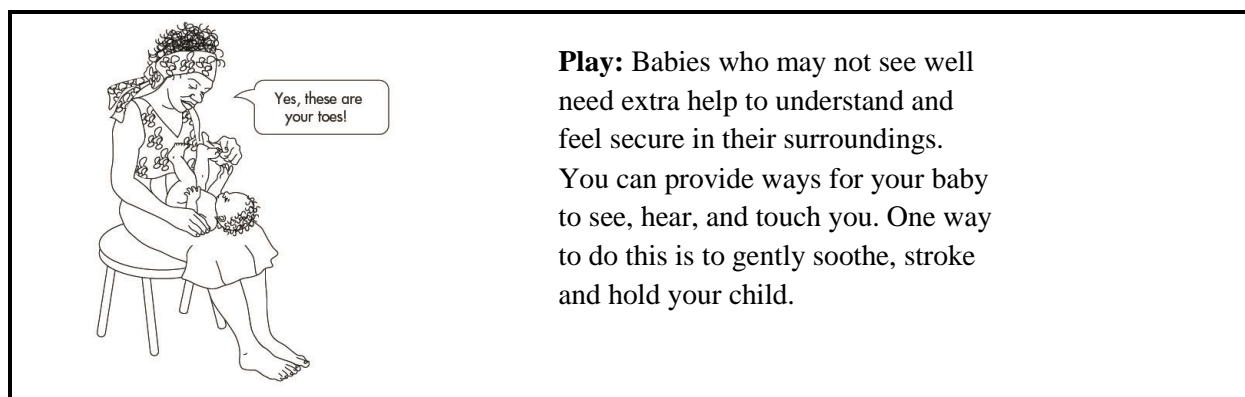
## Findings

### *Stage 1: Creation of training tools and training*

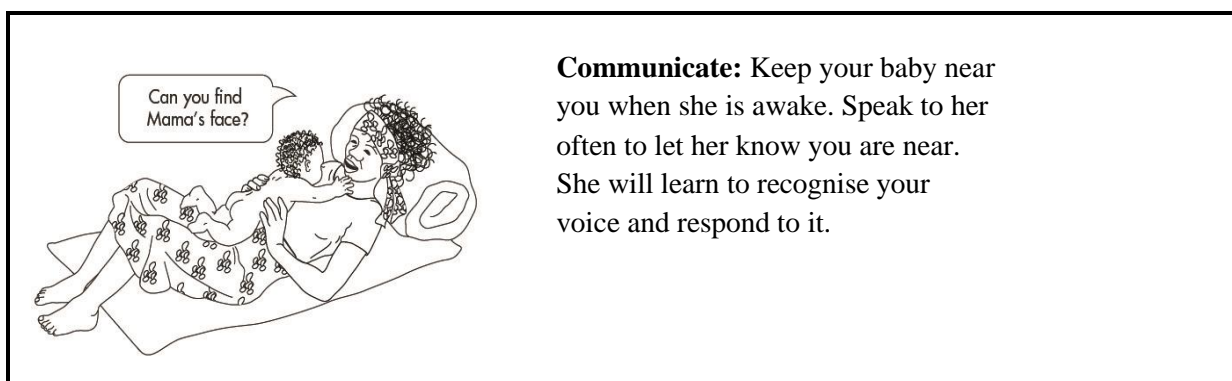
In preparing and adapting the materials, we integrated key areas that benefit all babies and young children with VI (e.g. accommodating for difficulties in social behaviour, joint referencing and early communication) in line with acceptable cultural practices (Cole, 1996). Materials recommended for parents and community workers drew on several existing training tools (Dale and Salt, 2010; Niemann and Jacob, 2000; Jennings, 2009) as well as the Malawi Development Assessment Tool (MDAT) in order to align developmental activities with milestones considered appropriate in the Malawian context (Gladstone et al., 2010). High quality line drawings of culturally appropriate mothers, family members, children with VI and play objects were created. We printed all counselling information, activities and drawings on laminated cards as well as on a single chart holding all activities. We kept instructions (Chichewa and English) to a few short sentences with some verbal prompts e.g. *Can you find mama's face?* The training was based on the child primarily having a VI with activities to develop tactile skills and functional vision. We designed a three-day training programme (two days based on CCD training and a third day for the feasibility study) to cover essential elements about childhood development and VI using small and large group activities, role-play and material development sessions.

The training package consisted of 16 separate counselling cards with eight play activities for different aged children (birth to 1 week, 1 week - 3 months, 3 – 6 months, 6 - 9 months and 9 months- 1 year, 1-2 years 2-3 years and 3 years +) and 8 recommending communication activities. A larger card captured all 16 pieces of advice which could be used by the community workers. Some modifications in the training were made for children with additional complex needs (e.g. placing a child with cerebral palsy in corner seat with a table to reduce slumping and facilitate the child's ability to grasp and play with objects). All carers were given the age appropriate laminated cards (see example in figure 2) to keep and use at home as well as a small number of low-cost locally sourced toys to help them to perform agreed communication and play activities (e.g. a rattle to increase child's ability to stretch arm and reach).

**Figure 2: An example of communication and play activities for carers to try with their children from birth to 3 months based on the WHO/UNICEF Care for Child Development Package**







## ***Stage II Piloting, fidelity and cost analysis***

The pilot ran over a six-month period (October 2013 – March 2014) with twelve visits conducted per child by a paired community worker in the three selected districts. The 15 community workers, each supported one to three children with visits taking an average of one hour mainly conducted in the home. Each visit usually consisted of the community worker sharing information about the child, discussing possible activities using the counselling cards, modelling the activity for the carer to see and then setting a small number of activities for the carer to try out between visits. Careful analysis of all the collected log-books revealed that community workers were able to visit homes on a regular basis (approximately once every two weeks) and then written follow-ups and reflections confirmed carers were broadly following workers' counselling and using the laminated cards at home on a daily basis.

### **Cost analysis of visits**

In terms of intervention costs, fixed payments were made to each community worker for the purchase of play materials - a one-off payment of \$4 (MK 3,000) for each child supported, and to cover subsistence for each visit (about \$4 at the time). The total fixed cost for the project was \$125 (MK 90,000) for playing materials for 30 children and \$1,510 (MK 1,080,000) for the 360 visits. Transport costs were more variable with average transport cost per visit at \$2.30 (MK 1,630). Total cost of transport for the six months was \$822 (MK586, 800), which was about a third of the total project cost (see appendix). Average transport costs differed across districts reflecting the complexity and length of the journeys with more rural districts costing \$2.84 (MK2,025) per visit (Chikwawa) and \$2.27 (MK 1,620) (BT Rural), compared with \$1.68 (MK 1,200) per visit in BT Urban.

The total intervention cost of the six-month pilot (including all travel, allowances and toys) was approximately \$2,420 with an average cost per child intervention of \$82. The analysis did not include paid staff salaries, costs of consultants, costs of development of training materials or family costs associated with these activities. Nevertheless, there were additional costs that also should be considered. The evaluation aspect of the project involved the cost of hiring an RA to conduct the field-work over 6 months (\$2,000) with additional fieldwork costs of travel and subsistence (\$8,000). While these are evaluation costs, in practice the RA also adopted a supervisory role given that she was also monitoring work had been effectively carried out. The cost of the three-day training programme (see previous section), which the community workers attended, (accommodation and subsistence costs were paid) is not included in this analysis. Additional hidden resources the project drew upon also included the infrastructure of the community workers - which was already in place. Similarly, the

costs associated with the development of the training tool materials and the input of the PI and Co-Is are not included in this analysis.

### ***Stage III: Acceptability of the Intervention***

#### **Affect of training on the carer and child (Microsystem: interacting factors in the child's immediate environment)**

##### ***Confidence and enabling the child to explore***

VI was seen as a substantial barrier prior to visits but after two-three visits, parents described that they were more likely to allow their children to go out of the house and interact with their peers.

...at first, I was not allowing the child to play with his peers because of his eye problem but now I allow him to go and play and through play, he is able to learn different things. I am also involved in his activities everyday by playing with him and make some playing materials for the child. (Carer (1) of boy, 3yrs, BT Rural)

We have learnt to allow her play with her friends and not to keep her indoors. We have learnt to teach the child to be independent. (Carer (1), BT Rural)

Carers described how they felt more enabled to communicate and play with their children because of the support they had received from community workers:

I have learnt a lot... like to help the child to sit and be flexible to move his arms and legs...I have learnt to use the blanket to support the child to sit by putting the blanket on his back... and let him also play with siblings or those around him giving him different things to hold in his hands. (Carer (2), of boy, 2yrs, BT Urban)

A small number of carers seemed to place considerably high expectations on their child's progress at times, particularly in relation to their ability to carry out everyday activities as well as changes in their disability.

I was expecting to see changes in the child's progress on his everyday activities comparing to those days when he was not visited. I was expecting to see the benefits of the teachers visit. Again, I was expecting to see my child getting well again. (Carer (3) of girl, 2 yrs, BT Urban)

I was expecting to see my child change for the better, to see him change his thinking capacity, knowing the benefits of play through interaction with friends and to be creative. (Carer (4) of boy, 3 yrs, BT Urban)

##### ***Understanding and communicating with the child***

Carers were able to find out better ways of understanding their children's needs by changing the way they communicated with them. This was more difficult for carers of children who had more complex needs. A carer of a three year old child with VI and profound multiple disabilities was more interested in learning about strategies that could help her to better understand her child's specific needs, particularly in relation to hunger, physical and emotional discomfort.

...the best way to communicate with the child is to be able to understand her by staying close with her thereby knowing when she wants something or not like when she is crying, the person sitting close to her will be able to know why she is crying. (Carer (5) of girl aged 4 yrs, BT Urban)

Another carer was better able to respond to her child's signing and pointing:

When the child is hungry ....communicates with me through...sign, ...moves ... head and points on my chest and that is when I realise that she is hungry. (Carer (6) of girl 4yrs, Chikwawa)

### ***Use of Stimulation objects and toys***

Three of the carers said they had made their own toys (e.g. a rattle, a doll stuffed with paper, a small throw-ball made out of foam). Community professionals also made low-cost toys (e.g. cars from wire coat hangers, a sorting game using coloured plastic squares.) The toys when introduced to children helped to provide 'stimuli' for playing and communicating.

At first, I was ignorant, I did not know what to do with my child but now I always play with him using different toys, which was hard for me to do before. (Carer (7) of girl 3yrs, BT Rural).

I used a tube (plastic bottle) filled with seeds... it rattles and I place it somewhere the child follows it. (Carer (7), BT Rural)

My child likes to play football. I made a football using local materials using plastic bags tied with string. (Carer (8) of boy 5yrs, Chikwawa)

One specialist teacher was able to use the different objects to demonstrate several learning activities – sorting utensils, cutlery and cutting shapes. Another teacher used songs, children's games, well known bible stories (e.g. Noah's Ark) with moulded clay animals. Some community workers also included the child's friends;

She, unlike before, is able to lead her friends into different games and is able to make the sounds of the animals in Noah's ark. (Carer (7), Blantyre Rural)

### ***Integration of stimulation and play in to everyday activities***

Most carers said that they were able to integrate activities demonstrated on a regular basis even though they said they would find it difficult to do so.

I always integrate the activities back home, repeating all ...activities with my child which the CBR worker introduced to me and my child every day. (Carer (1), BT Rural)

Now he is a changed person because each time you call his name and ask him to go and get something inside the house, he goes there and gets it..... He is now able to mention some of the things like the plates, pots, water because we always show them to him by mentioning their names. (Carer (9) of boy 5yrs, BT Rural)

### ***Acceptance of 'disability'***

Community workers encouraged carers to take more time to 'love', 'care' and 'respond' to their children. In the early stages, carers expressed a certain amount of reluctance to engage in

communication and play activities, mainly because of lack of awareness about what they could do. Many carers described how the visits enabled them to feel more accepting of their child.

They told us to start loving the children and not discriminate against them. I have learnt to love the child and give opportunities to play with peers. (Carer (2), BT Urban)

I learnt better communication...my child is blind...the teacher came and taught me how to communicate with her. I say her name and I tell her what I'm doing in the house so she knows. (Carer (10) of girl 2yrs, Chikwawa)

...the best communication is to avoid labelling him and accept discrimination. (Carer (8), BT Rural)

Although some carers felt relieved that community workers were providing help at home, in a small number of cases, the carer said they felt excluded from the training.

I was expecting to know the reasons of the teacher's visits...I do not know why he comes here. What I know and see is that he comes here to teach but I am not involved. (Carer (8), Chikwawa)

I was observing how he was teaching my child at a distance like playing with her using the toys and he was involving some of her friends too. After that, he was giving me the cards to keep.... I didn't learn anything....because I was not told the objectives of his visits and I was not involved... (Carer (8), Chikwawa)

### ***Affect of the training on the community (Microsystem and Mesosystem)***

#### **Forming better relationships within the community**

Visits from community workers resulted in forming better relationships not just with carer and child but also with their community. The workers encouraged carers to start taking their children out to meet and greet visitors when they passed them in the community and market. This seemed to open new windows of opportunity for social inclusion where carers lessened their hold on the child and allowed the community to engage with their child.

The relationship between the child and community has improved. More children are coming to play... It has become 'an eye opener' to the community. (Male carer (11) of boy 3yrs, Chikwawa)

Carers who have children with albinism, said they had been experiencing difficulties in encouraging others to accept their children and keep them safe. This may have been a result of recent media attention to the sporadic kidnapping and killing of children with albinism in Malawi and Tanzania.

A child with a disability (albino) is just like any other child, he needs same things, we do more things together...taught me how to work with my child. The project has helped the community to accept them more. My children (two with albinism) would be kept in isolation before. (Male carer (12) of girl 5yrs, BT Rural)

### ***Affect of the training on pre-school and primary education (Mesosystem/exosystem)***

Some carers did not feel confident enough to leave their child with another carer because of their particular needs (e.g. regular feeding, difficulties managing crying and general discomfort). This lack of multiple caring could also have had an impact on choices mothers made when deciding to enrol their children into a CBCC and primary school.

Through the training, some carers were encouraged to bring their children to local preschools particularly as they were able to see how their children were able to interact in-group activities.

With going to school (CBCC), there are so many activities she can do...teacher has a box of materials, plastic toys, with the visits of the teacher, I sometimes take the materials in the box and play with the child. Sometimes the child brings the box to her. (Carer (8), BT Urban)

Parents of older children who then attended pre-school or primary school began to think more positively about their child's future. Some described how the training had helped change their attitude to their children and to think about a more positive future for them.

When his friends sent their children to school.....I wouldn't let my child go to school because he can't see, but now I want to send my child to school. (Carer (13) of boy 5yrs, BT Urban)

There was some concern among parents that schools were unable to support their children's learning needs and there was a general lack of knowledge about the role of specialist teachers for children with VI. In a very small number of cases, specialist teachers trained to support children with VI were able to provide advice to parents about access and learning of Braille.

## **Discussion**

This is the first study, which has demonstrated the feasibility of utilising an adapted form of the WHO/UNICEF Care for Child Development training for children with disabilities, specifically for those children with visual impairment. It has demonstrated how children with VI and their carers have benefited consistently through a training programme at many levels (micro-exosystem).

Parents reported benefits from the programme at microsystem level and made it clear how they felt supported with the use of the cards and involvement of community workers. Without it, many parents said that they would still be experiencing considerable barriers in supporting their children at home and in the community.

The study has shown how vital it is for the training programme to be meaningful to carers and to fit into busy daily routines (running a household). The introduction of counselling activity cards and regular visits from non-local community workers could have a disruptive and negative impact on existing family arrangements. We found that interventionists need to respect how families organise their family activities on a day-to-day basis (Weisner, 2000; Gallimore, et al., 1999). Carers were more likely to integrate activities that fitted more to their daily routine (e.g. preparing groundnuts or maize or cleaning or carrying water). They often have to leave home in order to buy food, tend to the land, or carry out income generating activities during the day. Any rapid, unpredictable changes in caring for their child could have a negative impact on this routine. Carers found it easier to integrate communication activities such as singing songs or talking whilst carrying out household chores (Weisner, 2014; Gallimore et al., 1999).

The training programme has encouraged parents to spend more time communicating and playing with their children and enabled them to see their children as equal and capable of doing similar activities as

non-disabled children. In order to increase stimulation, community workers helped carers by providing them with ideas on how to make toys using locally sourced materials particularly those that make a sound (e.g. spoon and pot). These additional resources help carers to engage in their children's play on a more regular basis and make play rewarding for the child and carer.

Carers who were previously reluctant to involve family and community members because they were worried about safety and protection of their children, felt more confident about allowing their children, particularly girls, to play outside the home, similar to previous reports (Plan International, 2016), including at the local early childhood development centre. There was still a strong tendency for the community worker to 'control' the training of the child with little opportunity for the carer to practise and receive guidance. There was also a tendency for the community worker to work with the child and not withdraw in order to allow greater carer-child interaction. This more hands-on rather than 'coach' role created some confusion and misunderstandings about the visits.

Emotional and physical 'enablement' seemed to be inextricably linked. The child's personal space was often their own home but it is the outdoor spaces, which was described by parents as being the place where children could access new sensory experiences (leading to building appropriate concepts of the social and physical world). During training, community workers were asked to develop activities that could facilitate a child's access to 'enabling environments' both inside and outside the home (Jennings (2009).

The feasibility study highlighted some serious issues around human resource capacity in education and social welfare to respond to the basic needs of families of young children with disabilities, particularly in rural areas where there can be considerable problems recruiting and maintaining community workers and specialist teachers (Gladstone et al., 2014). Only those families that are within a reasonable travelling distance (up to one hour) are likely to be placed onto an existing work caseload by a specialist teacher or community worker. The current and foreseeable situation of chronic under-sourcing of human resources for early childhood development relies on individual good will, knowledge and availability of services. Such heavy reliance on individual and NGO support is unsustainable and cannot be justified particularly with so much lip service being paid to developing ECD in Malawi and elsewhere.

The study was able to demonstrate that it is feasible to integrate provisions of advice and information to carers of children with visual impairment in the early years into the *Care for Child Development* but could be expanded to include children with other disabilities. This might include adapted training programmes children with hearing impairment, cerebral palsy, intellectual impairments, and autism.

## **Reflections and Conclusion**

This study sought to strengthen ties between the Education, Social Welfare, Community Development and Health Services at district level and with UNICEF and WHO at national and global levels. By engaging community support workers from a variety of cadres to provide inter-agency ECD collaboration to the identified families, we were able to demonstrate how very basic support to families with children with VI can have a positive impact on the developmental and educational prospects of these children. Evidence from this study indicates that multi-sectoral collaboration, including cooperation between different governmental and non-governmental agencies, is an important component of successful early childhood initiatives. Integrating health, education, social and economic development is vital to develop a supportive environment and the services necessary to

support childhood development, especially among the most disadvantaged - children with disabilities. We found that ECD is a challenge because governance is spread across multiple sectors (education, social welfare and health) with the absence of clear planning and progress on even basic issues such as training of ECD providers. The acute lack of trained professionals in the ECD sector in childhood disability cannot be ignored if children with disabilities are to play an important part in the SDG agenda ensuring children do not only survive but also thrive. By engaging support workers from a variety of cadres to provide inter-agency ECD collaboration to families with disabilities, the study has provided evidence on how very basic support to families with children with VI can have a positive impact on the developmental and educational prospects of these children. Finally, applying Bronfenbrenner's bioecological model for ECD and VI has been valuable in helping the research team take a more 'holistic view' of a child's development in their immediate and external environments and the progressive accommodation that can be enabled between the carer and the child. This approach has been able to make explicit the links with the home, pre-school and primary school and the child's developmental and learning journey *to* them and *within* them. It would be reasonable to consider how this model could be used for other childhood disabilities in Malawi and within LMICs.

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The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

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**Box 1: Ten key messages for new ECD training programmes for children with visual impairment**

1. Important to provide advice on communication and play for children with VI.
2. Existing programmes can be adapted within the universal child development programmes e.g. child development with additional training.
3. They should facilitate earlier inclusion into ECD centres and primary school settings including advice to caregivers and teachers on how to support children with disabilities.
4. Multi-sector approaches could be considered including the use of 'champion' community workers e.g. child protection officers.
5. Need for increased emphasis on parent child interaction, bonding responsiveness, reciprocal communication and being attentive to VI child's needs.
6. Extensive use of role play within training using different toys, objects and scenarios – community worker with carer and child.
7. Enable the carer to model good practice and show carers new ways/ approaches of stimulating their children.
8. Increase awareness of integration of daily activities encouraging child with VI, saying child's name, developing manual competencies e.g. daily living skills.
9. Provide plenty of encouragement and support to carers even if they do not carry out instructions left on previous training visit.
10. Any further evaluations of programmes should not only include measures of child development but also inclusion and participation of children in community settings in the early years.

**Table 1: Costs associated with the training programme carried out by 15 community workers in three districts of Malawi (Blantyre Urban, Chikwawa, and Blantyre Rural). Cost presented in Malawi Kwacha (MWK) unless otherwise stated (US\$ based upon 1MWK to \$0.0014, the rate at time of writing)**

<b>COMMUNITY WORKER / DISTRICT</b>	<b>No. of children</b>	<b>Total visits per community worker</b>	<b>Total transport cost (6 months)</b>	<b>Average transport cost per visit</b>	<b>Total costs for staff allowance (MWK 3,000 / visit)</b>	<b>Play Materials (MWK 3,000 / child)</b>	<b>Total</b>	<b>Average cost per child</b>
<b>Blantyre Urban</b>								
BTU1	3	36	52,800	1,467	108,000	9,000	169,800	56,600
BTU2	1	12	12,000	1,000	36,000	3,000	51,000	51,000
BTU3	2	24	24,000	1,000	72,000	6,000	102,000	51,000
BTU4	1	12	12,000	1,000	36,000	3,000	51,000	51,000
<b>Sub-total</b>	<b>7</b>	<b>84</b>	<b>100,800</b>	<b>1,200</b>	<b>252,000</b>	<b>21,000</b>	<b>373,800</b>	<b>53,400</b>
<b>Sub-total (US\$)</b>	<b>-</b>	<b>-</b>	<b>\$141</b>	<b>\$2</b>	<b>\$353</b>	<b>\$29</b>	<b>\$523</b>	<b>\$75</b>
<b>Chikwawa</b>								
C1	1	12	42,000	3,500	36,000	3,000	81,000	81,000
C2	1	12	38,400	3,200	36,000	3,000	77,400	77,400
C3	2	24	60,000	2,500	72,000	6,000	138,000	69,000

C4	2	24	24,000	1,000	72,000	6,000	102,000	51,000
C5	2	24	30,000	1,250	72,000	6,000	108,000	54,000
<b>Sub-total</b>	<b>8</b>	<b>96</b>	<b>194,400</b>	<b>2,025</b>	<b>288,000</b>	<b>24,000</b>	<b>506,400</b>	<b>63,300</b>
<b>Sub-total (US\$)</b>	<b>-</b>	<b>-</b>	<b>\$272</b>	<b>\$3</b>	<b>\$403</b>	<b>\$34</b>	<b>\$709</b>	<b>\$89</b>
<b>Blantyre Rural</b>								
BTR1	3	36	54,000	1,500	108,000	9,000	171,000	57,000
BTR2	2	24	60,000	2,500	72,000	6,000	138,000	69,000
BTR3	2	24	43,200	1,800	72,000	6,000	121,200	60,600
BTR4	2	24	12,000	500	72,000	6,000	90,000	45,000
BTR5	3	36	76,800	2,133	108,000	9,000	193,800	64,600
BTR6	3	36	45,600	1,267	108,000	9,000	162,600	54,200
<b>Sub-total</b>	<b>15</b>	<b>180</b>	<b>291,600</b>	<b>1,620</b>	<b>540,000</b>	<b>45,000</b>	<b>876,600</b>	<b>58,440</b>
<b>Sub-total (US\$)</b>	<b>-</b>	<b>-</b>	<b>\$408</b>	<b>\$2</b>	<b>\$756</b>	<b>\$63</b>	<b>\$1,227</b>	<b>\$82</b>
<b>TOTAL</b>	<b>30</b>	<b>360</b>	<b>586,800</b>	<b>1,630</b>	<b>1,080,000</b>	<b>90,000</b>	<b>1,756,800</b>	<b>58,560</b>
<b>TOTAL (US\$)</b>	<b>-</b>	<b>-</b>	<b>\$822</b>	<b>\$2</b>	<b>\$1,512</b>	<b>\$126</b>	<b>\$2,460</b>	<b>\$82</b>

